Edmund G. Howe, " 'I'm Still Glad You Were Born' — Careproviders and Genetic Counseling," *The Journal of Clinical Ethics* 18, no. 2 (Summer 2007): 99-110.

"I'm Still Glad You Were Born" — Careproviders and Genetic Counseling

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In this issue of *The Journal of Clinical Ethics,* in "Uncertainty and Moral Judgment: The Limits of Reason in Genetic Decision Making," Mary T. White asks several ethical questions involving genetics. The most important of these may be the extent to which we, as careproviders, should abandon our traditional allegiance to being ethically nondirective.

We should consider this change due to recent advances in genetics that have increased the benefits of genetic testing. This following case is an example: a 48-year-old woman tested positive for the BRCA1+ gene and so was considered to be at high risk of acquiring ovarian cancer, but she refused follow-up evaluation and care. Her genetic counselor chose to be radically directive, and called the woman regularly over 12 months, urging her to have further evaluation until eventually she sought treatment. It was found that she did have ovarian cancer, and her surgeons, fortunately, were able to remove it all before it spread.[1] Whether the counsellor should have taken this approach is open to question,[2] but in this case it may have been lifesaving.

We know that some patients make decisions that do not seem to be best from an objective point of view. Some patients' decisions do not even seem to reflect their actual desires. Why might this happen? In some instances, patients may be at great genetic risk, but engage in total denial. They may, like the 48-year-old patient, not take measures that could save their lives. Unlike that patient, they may not agree to genetic testing that could help them determine what else they should do. When we are more directive with patients, we may be able to help them overcome their denial, and so this approach seems worth consideration.

But there are also well-recognized risks that caused genetic counselors to be nondirective in the first place. For instance, it is feared that we may impose our own moral views on patients, which may violate their autonomy and harm their self-esteem. If patients feel anger or depression in response, this may change the decisions they make; for example, if they are angry, they may choose not to go for genetic testing because this is what we recommend. Or, when we are directive, some patients may feel that we are telling them what to do, and they may feel less self-esteem and not go for testing because they feel "down" on themselves. Some patients may be so offended that they won't return for follow-up counseling and suffer a worse ultimate outcome. Given these concerns, should we be more directive? And if we should, when?

Readers may ask why genetic counseling shouldn't be left to genetic counselors, who receive special training. The answer is that the number of patients who may need or benefit from genetic counseling is far greater than what we may assume, and the number of genetic counselors is far short of being able to meet patients' needs.

As a result, in most cases, patients will depend on the careprovider they usually see for genetic counseling. How patients fare with genetic illness often is not determined by the seriousness of the disease — at least until its final stages — but rather how they perceive their own situation.[3] The implications of these findings for careproviders are immense: what we do may actually determine patients' outcomes, for better or for worse.

GENERAL PRINCIPLES

To help patients gain the most from genetic counseling, we should focus on establishing and maintaining our relationships with them and to maintaining their self-esteem. Without the relationships we may have no patients left to treat; patients who feel badly about themselves often make poor decisions. If we choose to be directive, we may violate patients' denial, and the patient/careprovider relationship may be "fatally" changed: patients may no longer feel safe enough to discuss their genetic options openly with us.

Patients may also feel that we "talk down" to them,[4] which may infantilize or anger them, and threaten their self-esteem. Perhaps the patients suffered some loss of self-esteem when they first learned that they might have a genetic illness (or be a carrier).[5] The loss may occur due to feeling a change in identity or feeling fear. Greater loss may occur if they later go for testing, whether the results are positive, negative, or uncertain. Patients who lose a relationship with a careprovider, or who lose self-esteem, may make decisions that are based not on what they really want, but on what they feel. They may seek out additional information from their careprovider, not to help make a decision, but to rationalize a decision they have already made based on emotional reasons.

Patients tend to make genetic decisions on the basis of their feelings, and, as Mary White notes, these decisions are often "non-rational." That patients tend to make genetic decisions based on non-rational or irrational feelings has led to an important finding: most patients must be emotionally engaged to benefit from genetic counseling.[6] This makes sense, as persons don't usually make personal decisions based solely on statistics. Thus, if patients make genetic decisions based on feelings, and the feelings are irrational, the only way to help patients may be to help them change their feelings. The best way may be to directly engage their emotions. Recent studies suggest that we can engage patients' emotions most effectively when we share a relationship with them that is safe and trusting.[7] There are ways that we can be directive and also reduce the risk of harming patients.[8] Two of these approaches are especially promising.

THE "MAGIC" OF SAYING *WHY*

Patients who face genetic illness state repeatedly that what they need most, in addition to genetic information, is emotional support from their careproviders (and others).[9] In general, if we can express any positive feeling — verbal or nonverbal — that is genuine and caring, it will enhance our relationship with patients and enhance their self-esteem. Although this is not difficult to do, we may not do it; all too often patients bitterly say their careprovider "doesn't seem to care." Showing that we care is especially important when we do genetic counseling and try to engage patients emotionally, even though this may be incompatible with conventional nondirective counseling.

An example of what I call the " 'magic' of saying *why*" makes this case. A patient called me and said he had sudden strong impulses to take his life. He had been in a therapy group and there met a new best friend — actually, his sole friend. When he shared with the group that he and the other group member had become friends, the leader of the group told him that he could not continue to participate in the group and continue to meet outside the group with his friend. (This is a routine "rule" in certain kinds of group therapy, and the group leader probably provided guidelines when the group had started to meet, but the patient apparently missed that, and felt beat up.)

Over the phone, with the patient still feeling acutely suicidal, I tried to explain *why.* "It's a 'ground rule,' virtually always the case in groups like this. When your doctor said this to you, it wasn't at all personal. The assumption underlying this rule is: if any person from the group meets outside the group with a friend from

the group, the friends may share what is most important with each other, but not with the whole group. Then, patients may not benefit from the group."

"Oh," he said after a silence, and then reported that his suicidal feelings had "disappeared."

If we aren't the kind of persons who experience such sudden, profound shifts in feelings, we may not know that this kind of shift can occur. Regardless, in patients whose emotions are labile, this kind of shift isn't uncommon. What I hope to show is the profound and possibly lifesaving results of taking time to explain *why.*

During genetic counseling, patients sometimes ask careproviders what they would do, if they were in the patients' situation.[10] Should we refuse to answer, patients may experience this as an assault, especially since they took the initiative and found the courage to ask. There are some examples in the medical literature that illustrate how we should not respond — although these responses may still be recommended today. One recommended response is to say: "I'm wondering if you wish that someone could tell you what to do." Another is: "What are you hoping that I'll say?" Still another is: "Perhaps you wish that I could tell you the 'right' answer."[11] These responses correctly intend to gain information, but they all risk harming the relationship and patients' self-esteem by conveying to them that we have more knowledge about the patients than they do, themselves. Based on our response, patients may feel that they are being talked down to.

Yet another recommended response is: "I'll answer, but only if you first explain to me your reasons for asking."[12] This is also a mistake, as it also may convey that we see ourselves as knowing more about patients than they know about themselves and, thus, are talking down to them. What can we do instead?

We could say we will share what we would do, but would like to ask first for the patient to identify what he or she hopes to gain. We can explain: "If I answer your question first, then you may not know what you are hoping I might say, and that information about yourself could be very important as we work together to enable you to decide what you want to do." We can say: "As you know, what I would do may be the total opposite of what you should do. Only you have lived in your shoes your whole life, so only you know what is most important to you."

A separate question is whether we should take the initiative to offer what we would do even when a patient doesn't ask. We can obviously ask every patient if she or he would find this helpful, which is clearly the opposite of being nondirective. We can even encourage patients to answer "no," and say, "I have a sense of what I might do if I were in your shoes. You might find that useful — or not. Maybe you feel you have all the information you want, and don't want to discuss anything else. If you think my telling you what I might do would help, I will. What would you like?"

Taking this approach serves several positive ends. First, the information may benefit the patient. Second, taking the initiative to offer advice to all patients avoids discriminating between patients who are assertive and ask for help and those who are not. Third, offering in this way has a personal, caring connotation. When we go further to try to maximize the chance for a good outcome, it conveys to patients that we care about them.

THE MAGIC OF ANTICIPATING AND FOREWARNING

As noted above, should we choose to be more directive, it may adversely affect our relationships with patients or their self-esteem. A way to reduce this risk is to anticipate any ambiguous meanings in what we plan to say and forewarn patients that what we say could be misinterpreted. We can say that what we plan to say is directive and intended to be helpful, but it may seem as though we are trying to impose our own view. This may cause resentment, and given this, should we continue?

We have to anticipate that patients may misinterpret what we say and respond negatively whenever we do anything more than just provide information. This is particularly important in genetic counseling, which includes asking patients to reflect — asking questions about feelings they may want to deny, which can feel threatening.

As a hypothetical example, perhaps a patient is trying to decide whether to abort a fetus she has learned has a very serious genetic disease. She says to her careprovider, "I know that my having an abortion would

be best for my family." Her careprovider, wanting to engage her emotionally, might ask, "But how about you?" because he noticed that she remained silent after speaking, suggesting that she was somehow stuck emotionally after saying this. In these kinds of situations, there are any number of mildly directive, more reflective questions we can ask patients to try to engage them emotionally.

But, as noted before, these kinds of questions may threaten a patient's denial. In the above example, for instance, the patient might experience her careprovider's prompting query as "pushing her," and as an attempt to impose his bias against her decision to have an abortion. To do our best for our patients, we must try to reduce the risk that a patient may make a wholly unwarranted inference. We can reduce the risk by trying to anticipate this and say something such as: "I want to ask you something that may feel as though I am pushing you a bit. Maybe you won't think that, but it's possible, even when that isn't my intent. You might feel resentful, because that's how we all work — we can't help it. So, knowing this, do you want me to go ahead and ask you a question that might cause some pain?"

Of course, if we ask this, some patients may answer falsely because they are exceptionally compliant. As Darlyn Pirakitikulr and Harold J. Bursztajn state in their article in this issue of *JCE,* "Pride and Prejudice: Avoiding Genetic Gossip in the Age of Genetic Testing," for example, "frightened and demoralized" patients find it "easier to go with the flow" than to initiate an objection. What this means is that some patients would find it hard or nearly impossible to say "no" when their careprovider asks, "Is it OK for me to ask you something that may hurt?" They may be like the 48-year-old woman who wouldn't go for treatment for her ovarian cancer, even though it was possible that she might die; she was denying that she was at high genetic risk. The hypothetical patient above who said she knew that having an abortion would be better for her family may not feel emotionally ready to discuss her own desire — if she has such a desire — to go against what she sees as her family's best interest and bear her child.

We may find that it is difficult emotionally to bear patients' avoidance. Yet, patients must be prepared for what they will experience, and we must be prepared to accept these kinds of situations and the helplessness that patients may feel in response. It is essential that patients know their full range of options and the risks of each option. When patients know this and then want no more discussion, we must accept that the best we can do may be to maximally support their denial, rather than confront it.[13]

Patients may have denial for many reasons. In the case of the patient with the BRCAI+ gene, the patient may have needed denial to retain her sense of hope.[14] We don't know whether the value of retaining hope (if that is the reason for the denial) should outweigh the potential gain of testing or treatment. I would suggest that to prepare patients in the ways just suggested, but not go further, may be the best that we can do.

SPECIFIC APPROACHES

Patients and their careproviders may feel confident that they can know how patients will respond to agreeing to genetic testing, whether the findings are positive, negative, or uncertain. In fact, this may not be the case. For example, a patient may have great anxiety prior to being tested, but this higher level of anxiety about being tested may not predict how she or he will respond later, after receiving the testing results. The patient's anxiety may "go," actually, in the opposite direction.[15] Accordingly, we shouldn't ever conclude that a patient won't benefit from counseling, even if the patient appears to be and reports to be wholly calm. Rather, we should presume that, for most patients, genetic counseling will be significantly beneficial,[16] and we should tell patients that their prior feelings, no matter how calm, may be misleading. In any event, the following suggestions are meant to apply to all patients.

PATIENTS WHOSE FINDINGS INVOLVE MOSTLY THEMSELVES

Some of the following approaches apply to giving patients information. They are not about genetic risks, but about the risks for patients that are related to the process of deciding to be tested or to the consequences that may be experienced when choosing to be tested. Many may appear to be nondirective, as they involve only giving information, but this assumption is mistaken, as the connotation of the information may be highly directive. Thus, the general principles outlined above regarding directiveness apply.

Helping patients to consider counseling. A first concern is that a patient may not know that she or he could benefit from counseling and so, to their detriment, decline it. Accordingly, we should take the initiative to inform patients of the two empirical findings stated just above: (1) some patients may find the experience of deciding whether to undergo genetic testing and/or the findings emotionally extremely "difficult," but may not suspect this; (2) most patients may benefit from genetic counseling, both before and after testing, especially if they can become emotionally involved. We can tell patients that no matter how savvy they may be, when it comes to genetic illness, they may have some emotional fears that even they can't detect --fears that are in an emotional "blind spot," so to speak. In this situation, the additional eyes and ears of a counselor may be helpful to them.

Helping patients to decide whether to seek testing. We may be tempted to urge patients to be tested when the results could benefit them greatly — perhaps even be lifesaving. If we express our own bias, even inadvertently, however, it may be counterproductive. Instead, we should tailor our interventions to the particular stage of awareness the patient has achieved. Earlier on, patients may simply not feel ready for testing. In this circumstance, the most helpful thing is to support patients' feeling that they need to wait. We can say that for now the most important thing is to retain hope and not pursue testing. We can add that the patient can change her or his mind later, and that this reconsideration may take some time.

If waiting may significantly increase patients' risk, we should ensure that they know this. It may be especially important to support patients at this time, particularly if others urge them to be tested against their will. It seems paradoxical that we can best help patients by respecting and supporting their choice, even when this is to avoid testing. If we do this while making patients aware of the risk, we may help them overcome their fear sooner. We may also help them avoid feeling shame; later, if they become ill, others may want to blame them for delaying testing, and the shame they may feel might harm them as much or more than their genetic illness.

We can also help patients by alerting them to the possible risks of seeking too much information. This may also seem counter-intuitive, as we may not be able to imagine that seeking out more and more information may, at some point, become self-destructive. Patients may feel virtually driven to it. Patients who do this may be the opposite of those who are harmed from having too much denial; they may be "compulsive information seekers." Patients may become so frightened by the information they acquire that they can't get the information out of their minds. Simply stated, it "haunts" them. They seek out the "worst-possible scenarios" and then can't get them out of their minds.[17] This exhaustive worst-case scenario information may so overwhelm patients that they "shut down" emotionally. Then they may avoid testing, even though it is most beneficial.

As this may be the case, we should take the initiative to inform patients that, on the one hand, while it is important to consider possible worst outcomes, it is as important not do this to an excessive degree. We can tell patients that they may not be able to avoid "obsessing" about what they know, but they may be able to consciously stop seeking out more information. We can encourage patients to discuss any medical experiences that they or others may have had that have upset them. We can say that we urge this because those upsetting experiences may bias or even determine patients' decisions. Finally, we can ask specifically whether any of their own or other persons' medical experiences have upset them recently — say, in the last year.[18] If patients answer "yes," we should advise them to take more time to decide about being tested, as long as doing this wouldn't significantly increase possible risk.[19]

This is directive advice, and is based on the finding that most persons need at least a year to recover from very upsetting events, and if they have to make a decision before a year (or more) has elapsed, their upset feelings may dictate the choices they make.

Preparing patients for positive, negative, and uncertain results. Patients may become profoundly emotionally disturbed after receiving genetic results, whether these results are positive, negative, or uncertain.[20] It is empirically known in many clinical contexts that patients who are prepared and expect what may

occur fare better than patients who are not prepared. This may especially be the case for patients who receive the worst possible news, but have been able to anticipate that this might occur. An example of this truism is patients with cystic fibrosis (CF), now the most common life-threatening genetic disease in the U.S. The statistical life expectancy for people with CF is now the middle or late thirties. Some people with CF do as well as others without the disease as they grow older, however, in large part because, in addition to support, they have learned what to expect and have had time to adjust.[21]

To sum up, when patients do decide to be tested, we can help them greatly by preparing them for the various possible results.

Positive results. The most important way we can help patients in the event they test positive for a genetic disease is to inform them that what patients experience, even when they have the most serious genetic disease, may depend more on how they perceive their disease than on the disease itself, at least until its final stages. It may have an exceptionally great impact to say this *before* patients go for testing. If it is related after patients test positive, patients may feel we are just saying this to help them feel better. Further, if it's said beforehand it may "pop" into patients' minds later, when they most need it.

Some patients, even those who have the most serious genetic diseases such as Huntington's, are able to find different and new sources of meaning and joy even after they learn they have such a disease. Patients may find new meaning in each moment of their lives that they hadn't and perhaps couldn't have before. They may also help others find new meaning as they cope with their disease with as much dignity as possible. For example, patients may want loved ones to have a positive memory of how they were, and hope to inspire them to cope as well with any adversities that they encounter.

By telling this to patients beforehand, we may plant the seeds of these thoughts. We can acknowledge with patients that these things may be easy for us to say, because we aren't about to be tested! And on this basis, it would be understandable if patients feel resentful about our comments. We should also acknowledge, though, that we are sharing the information before the testing (1) because it's true, and (2) because patients may be better able to hear it before testing, rather than after. As I mentioned above, patients may remember this, and it may provide a ray of hope later on.

Another major way that we can help patients who test positive is to help them anticipate possible stigma, which may even occur within their own families. We can also tell patients that stigma may occur even if they are "only" a carrier. As Pirakitikulr and Bursztajn state, "lay people" often believe that "a mutation equates to the presence of a malady." Stigma is due to centuries of irrational attitudes. If we are able to address and even attack the irrationality of stigma before it occurs, its harmful effects may be disproportionately less. This claim may seem exaggerated, but recent empirical data indicate that even remarkably brief interventions by teachers can markedly change the invidious effects of both racial discrimination and gender discrimination. As a consequence, persons affected by stigma may do surprisingly better.[22] One writer reviewing the extent of this impact has described it as "remarkable." Another, an expert in this field, says that these studies go " 'far beyond what you might expect from the simplicity of the interventions.' "[23]

My favorite example illustrating this involves a patient who has an evident facial imperfection. When she was a child, other children mocked her, and she felt great hurt and shame. When she was 12, she described this to a doctor when they were in a room that had a blackboard with chalk. At hearing this, he grabbed a piece of chalk and threw it against the blackboard hard enough to shatter the chalk, and said, quietly, "Makes you feel angry, doesn't it." She never again felt the same sense of hurt or shame.

The "lesson" is unmistakable — when just one careprovider says something like this, it may be enough to change a patient's life.

Negative results. Patients may have exorbitantly painful emotions even after they receive negative testing results. There are many reasons; for example, they may remain unconvinced they do not have the disease. For this reason, some careproviders recommend that, routinely, when patients have negative results, careproviders should schedule a follow-up visit several months later.[24] At this visit, we can evaluate whether

patients have had difficulty believing their negative results. If so, we can reaffirm the negative results. Patients may have painful feelings because someone related to them is positively affected. They may experience what is commonly called survivor guilt.[25] They may feel intense emotional pain in this situation because they have lost their (presumed) "shared genetic identity" with a loved one, and after testing negative they may feel more distant and estranged.

Or the negative results may destroy patients' prior "identity." Some patients assume that they have the genetic disease their parent had, will suffer from the illness, and perhaps die prematurely. For example, a patient psychologically identified with her mother, who had Huntington's disease. When she tested negative at age 20, she said, "the one constant thing in my life has now been taken away."[26] This belief isn't wholly rational. Still, patients may become emotionally convinced of this from the first time they learn that a parent is affected.

When patients learn that they aren't affected by the disease, it may shatter their prior beliefs regarding who they are and what they expect. They may, for example, never get married or have children, because they "know" that they have this disease.[27] If patients are told about these three possibilities before testing — that they may not believe negative test results, that they may feel much worse after testing due to survivor guilt, that they may lose a sense of themselves that they have had their whole life — it may help them to accept these feelings later, if they occur. More importantly, it may also help them to see these responses as "normal." They may then not experience, in addition to these other responses, the feeling of shame.

Uncertainty. Test results may be uncertain, which may occur in either of two ways: the predictive value of the results may be low, or "modern medicine" does not currently know what the results mean. We can help patients prepare in either case. The first thing we should tell patients is that most patients find the feeling of uncertainty most difficult to bear. For example, patients who might have Huntington's disease may prefer the certainly of an unambiguous test result — even a positive result — than to live in uncertain fear.

For this reason, many patients choose to be tested. Some genetic tests may indicate that patients are at greater risk, but the extent to which this changes their possible outcome is marginal. Under these circumstances, patients may not gain much useful knowledge from testing, but knowledge of their increased risk may greatly increase their anxiety. As a result, patients may do better if they choose not to be tested. When the medical profession doesn't know what some genetic results mean, patients may face no known risk but may also feel markedly increased anxiety.

This anxiety may significantly interfere with the quality of their lives. So, in advance, we should inform patients how they may respond to whatever kind of uncertainty they can foresee, and this knowledge may or may not significantly influence their decisions. It may help them to accept that they may experience anxious feelings, and to not feel shame if they do. The seriousness of such feelings are illustrated by the experience of a man who was caring for his wife as she died. As time passed, he felt increasingly distressed and, in his words, "became unglued." He felt profound pain and grief on his wife's behalf, but he said that a greater and more unbearable feeling was shame that he wasn't "stronger." The feeling of shame caused him to have thoughts of ending his life, he said. (He didn't, and has since done well.)

PATIENTS WHOSE GENETIC FINDINGS INVOLVE OTHERS

When patients consider genetic testing, this testing often involves the interests of family members who are genetically related as well as patients' significant others and spouses. These concerns are much more complex in that they involve others.

Parents, siblings, and spouses. When a patient's decision to be tested involves other adults, it is ideal to be able to discuss key issues with all of those who are involved. We can try to persuade those who are involved to get together, and this may succeed in many cases. It may be very helpful for those involved to get together and improve their communication before the patient goes for genetic testing, because they may feel less stress prior to testing and more able to hear, as mentioned above.

The results of doing this may be disproportionately beneficial. For example, a man had been estranged from his father for 10 years, and when they first reconciled, the son spent their first hour together lambasting his father! For a decade, the father had spent all his holidays alone; after this meeting, however, the son, with his wife's agreement, has left her to join his father for every holiday. The effects of meeting to nurture loved ones' support for patients who may have genetic disease is similarly beneficial. As one teenager with cancer expressed it: "Well, you kind of knew that your family cared but they never really had a chance to show you. It kind of gives them a chance to show you."[28] Consequently, we should be directive and explore this initiative, and not be deterred if a patient is estranged from his or her loved ones.

Parents with serious genetic diseases may feel terrible because they will die prematurely.[29] We may be able to help parents and their children by enabling the parents to share this with adult children, if they haven't already. The principle is simple: Talk is likely to be better than no talk. If persons aren't speaking with each other, they most likely are holding their feelings within.

One of the greatest sources of distress in genetic testing is when siblings test differently.[30] If the siblings meet together before being tested, it may help them overcome this. Two sisters who had wholly different styles of coping were both at risk. They sought counseling together, before being tested. Now, both engage in optimal self-monitoring, and better still, perhaps, they report that "this conversation is part of their relationship."[31]

Meetings can also help greatly — often in a different way — for spouses, since their partners aren't genetically affected but live "side by side." For example, a wife was at high risk for breast disease but wouldn't go for genetic testing, and even refused to regularly examine her own breasts. The risk of not doing either of these was "lethal." She and her husband decided to go for counseling before she went for testing. In the end, she decided not to go for testing but agreed to examine herself every month. At her request, her husband reminds her to do so, "religiously."[32] It is particularly important for spouses to attend counseling when one may be at genetic risk, because the person who is at risk may be terrified that the partner will abandon her or him. This fear may be particularly pronounced if the person at risk observed this happening with an affected parent.[33] Even when a patient fears abandonment, we may be able to help the patient and her or his partner improve communication, which may wholly alter the couple's "fate."

Children. Our potential to positively affect what patients experience also exists when the other affected family members are children. An often agonizing issue for parents is deciding when to tell children that their parent has — or may have — a serious genetic disease. If the parent has this disease, the child may then have it as well. An example illustrating this wrenching dilemma is a parent who has myotonic dystrophy (MD). MD is an autosomal dominant disorder characterized by progressive muscle loss. Parents must tell a child that he or she also has MD when the child begins to show its manifestations, and this may be particularly difficult because MD may occur earlier with each successive generation.[34] Careproviders who encounter this situation might discuss three things with the parents.

The first is how the child will feel if the parents don't tell her or him in the longer run, but instead tell the child about this as early on as they can. This information may be most difficult for children to hear at any age, but, if parents don't share it with their child early on, in addition to feeling devastated, as the child will at some time in any case, the child may also feel bitter.[35]

The second is an argument that parents should not disclose that they and/or their child has or may have a serious genetic illness as early as they can. In most simple terms, parents might hold off because the information may cloud a child's capacity to experience joy in the present. This may be a reason that parents who are at genetic risk may not want to be tested. One mother said, for example, after she tested positive, " 'Now when I look at my daughters I see death on their faces.' "[36]

Third, if parents do tell their child, they may be able to support the child in ways that they otherwise couldn't. We could offer, as a group for consideration, children who have cystic fibrosis (CF) and their parents. Many of these children do well, although they usually know that they have this genetic disease from early on. The children come to know, also, that they will prematurely die.[37] When children who know that

they have CF are younger, their parents can imbue them with unparalleled self-esteem. This is exemplified by a father who has MD and a 50 percent chance of passing it on to his children. He has two children without MD, but the third child has it. He told her, "Well, I'm still glad you were born."[38]

As children grow older and enter adolescence, it may be very painful to fear that no one will want to marry them. Parents who have discussed their genetic illness openly with their children may again inculcate exceptionally positive feelings. In this situation, parents may help their children acquire the sense that what may be most important is whom they would want to marry for themselves. This might not be someone who wouldn't want to marry them because of their illness; this might be someone who would want to marry them regardless of their genetic illness, but solely because of who they are. Parents may help their children use this as a sort of litmus test for whom they might want to marry. An example of a man who "passes the test" follows: he married a woman with MD and comments, " 'On my father's side, there is deafness. . . . So it is just kind of, you know, nothing. You just come to accept flaws in people.' "[39] They plan to have children using prenatal testing, if they can.

Infants and fetuses. Parents may agonize over whether to have children who may have genetic illness, and what to do should they learn, during pregnancy or just after their child is born, that this is the case. If parents would be able to use pre-implantation genetic screening, we should take initiative to inform them about it, because they may not be aware that it exists.[40] Since some parents could find this offensive, we should use the general approach outlined above: we could tell parents why we raise this option and say that it is possible that they could take this the wrong way — namely, that we are implying that there is something wrong with a child who has a genetic disease. After we do these things, we should then ask the parents whether they want us to proceed. The hardest aspect may be that some parents will want to abort their child or let him or her die after birth, when we feel that although it is "legal," the parents' grounds for doing this aren't justifiable.[41]

Some reasons that parents may choose to let a fetus or infant die when he or she has genetic problems are more valid than other reasons. Parents may, for example, not want to have such a child due to feelings of shame. We may inform parents of this possibility; state why we do this; describe to parents how they may misinterpret our actions; ask them for permission to proceed. We can inform them that some parents, for unconscious reasons and without knowing it, may want to "extrude" such a fetus or infant from their family, so that their family can be "normal." We can pursue this further and say that if the parents feel this way, they may want to take more time with their decision, since feeling this way may be transient. They may regret it later if they make a decision too quickly.[42]

Still, we must keep in mind that some parents have greater capacities to raise children with serious genetic illness than others. The best any parent can do may be to decide what capacity she or he has, as best as possible. This may result in what may seem to be a repeat of what happened to a baby born with Down's syndrome and intestinal atresia at Johns Hopkins decades ago. The baby died due to water and food being intentionally withheld. I talked with a parent who made the same decision for an infant with most serious genetic disease. He held his son, day after day as he died, and as water and food were withheld. The baby, the father tells me, at the end, had the beginning of gangrene in his legs and stopped breathing, periodically, for many seconds. This may seem to be gruesome, but we must, above all else, fully support parents if and when this occurs. We should give our support even when parents legally can and do make decisions with which we strongly disagree. This may be among the most difficult tasks we ever are asked to perform. Still, as leading authorities in the area state, "the quality of the decision making process should not be assessed on the basis of its rationality, but on the basis of the parental emotional outcome."43

NOTES

1. E.T. Matloff, "Becoming a Daughter," *Journal of Genetic Counseling* 15, no. 3 (June 2006): 139-43.
2. See comment on this intervention in P.M. Veach, "Commentary on Becoming a Daughter: Trauma is

a Powerful Teacher," *Journal of Genetic Counseling* 15, no. 3 (June 2006): 145-8.

3. See, i.e., S. McDaniel, "The Psychotherapy of Genetics," *Family Process* 44, no. 1 (March 2005): 25-44, p. 26, and P.E. Pfeffer, J.M. Pfeffer, and M.E. Hodson, "The Psychosocial and Psychiatric Side of Cystic Fibrosis in Adolescents and Adults," *Journal of Cystic Fibrosis* 2 (2003): 61-8, p. 63.

4. Feminist theory seeks to equalize power imbalance between therapists and clients. B.C. Thomas, P.M. Veach, and B.S. LeRoy, "Is Self-Disclosure Part of the Genetic Counselor's Clinical Role?" *Journal of Genetic Counseling* 15, no. 3 (June 2006): 163-77, p. 164.

5. K.S. Kendler et al., "Life Events, Dimensions of Loss, Humiliation, Entrapment, and Danger in the Prediction of Onsets of Major Depression and General Anxiety," *Archives of General Psychiatry* 69 (August 2003): 789-96.

6. S. Sarangi et al., "(Mis)alignments in Counseling for Huntington's Disease Predictive Testing: Clients' Responses to Reflective Frames," *Journal of Genetic Counseling* 4, no. 1 (February 2005): 135-55. See also, K.D. Valverde, "Why Me? Why Not Me?" *Journal of Genetic Counseling 1*5, no. 6 (December 2006): 461-3.

7. S. Sarangi et al., "Initiation of Reflective Frames in Counseling for Huntington's Disease Predictive Testing," *Journal of Genetic Counseling* 13, no. 2 (April 2004): 135-55.

8. R.J. Tassicker, "Psychodynamic Theory and Counseling in Predictive Testing for Huntington's Disease," *Journal of Genetic Counseling* 14, no. 2 (April 2005): 99-107.

9. Ibid.

10. Self-disclosure requests were more common from prenatal parents (34 percent) than they were from pediatric parents (6 percent). Thomas, Veach, and LeRoy, see note 4 above, p. 171.

11. Ibid., 174.

12. Ibid., 175.

13. "Resistance thrives when we and the patient are not allied around a common goal and are at different sates of change." D. Mee-Lee, "Engage Resistant Patients in Collaborative Treatment," *Current Psychiatry* 6, no. 1 (January 2007): 47-61, p. 51.

14. Valverde, see note 6 above, p. 463.

15. K.A. Rimes and P.M. Salkovskis, "Applying a Cognitive-Behavioral Model of Health Anxiety in a Cancer Genetics Service," *Health Psychology* 25, no. 2 (2006): 171-80, p. 172.

16. M. Keller et al., "Acceptance of and Attitude toward Genetic Testing for Hereditary Nonpolyposis Colorectal Cancer: A Comparison of Participants and Nonparticipants in Genetic Counseling," *Diseases of the Colon and Rectum* 47, no. 2 (February 2004): 153-62, p. 159.

17. See, e.g., A. Tluczek et al., "Newborn Screening for Cystic Fibrosis: Parents' Preferences Regarding Counseling At the Time of Infants' Sweat Test," *Journal of Genetic Counseling* 15, no. 4 (August 2006): 277-91, and P.A. Ubel, "Is Information Always a Good Thing?" *Medical Care* 40, no. 9 (supp.) (2002): V39-V44.

18. Sarangi, see note 7 above.

19. Ibid.

20. "Sharing the experiences of individuals who have previously undergone genetic testing with potential testees may be a useful strategy in this process, as normalizing reactions to health threats has been shown to be an important way of promoting good coping." N.A. Kasparian et al., "Better the Devil to Know? High-Risk Individuals' Anticipated Psychological Responses to Genetic Testing for Melanoma Susceptibility," *Journal of Genetic Counseling* 15, no. 6 (2006), *www.springlink.com.lrc1. usuhs.edu/content/m306wlk707r26282/fulltext.html,* accessed 12 January 2007.

21. Tluczek et al., see note 17 above, p. 278.

22. G. Cohen et al., "Reducing the Racial Achievement Gap: A Social-Psychological Intervention," *Science* 313, no. 5791 (1 September 2007): 1307-10; I. Dar-Nimrod and S.J. Heine, "Exposure to Scientific Theories Affects Women's Math Performance," *Science* 314, no. 5798 (20 October 2006): 435.

23. R. Adler, "The Curse of Being Different," *New Scientist* 193, no. 2586 (13 January 2007): 17.

24. Valverde, see note 6 above, p. 463.

25. Ibid., 462.

26. Tassicker, see note 8 above, p. 102.

27. Ibid.

28. R. Woodgate, "The Importance of Being There: Perspectives of Social Support by Adolescents with Cancer," *Journal of Pediatric Oncology* 23, no. 3 (May-June 2006): 122-34, p. 129.

29. "The biggest concern is leaving your own children motherless." Valverde, see note 6 above, p. 463.

30. McDaniel, see note 3 above, p. 27.

31. Ibid., 36.

32. Ibid., 36-7.

33. Tassicker, see note 8 above, p. 105.

34. McDaniel, see note 3 above, p. 32.

35. "June felt outrage at her parents." Tassicker, see note 8 above, p. 104. See also K. Holt, "What Do We Tell the Children? Contrasting the Disclosure Choices of Two HD Families Regarding Risk Status and Predictive Testing," *Journal of Genetic Counseling* 15, no. 4 (August 2006): 253-65.

36. McDaniel, see note 3 above, p. 30.

37. Tluczek et al., see note 17 above. CF is the most common life-threatening genetic disease in the U.S. (p. 278). The median survival age is now the late thirties (ibid.). See also Pfeffer, Pfeffer, and Hodson, note 3 above.

38. McDaniel, see note 3 above, p. 33.

39. Ibid., 35.

40. Pfeffer, Pfeffer, and Hodson, see note 3 above, p. 65.

41. Couples who have prenatal testing may have less difficulty when they have less certainty. Their "burden of decision-making" may then be less, and it may enable them to better " 'hope' for the best." H. Bijma et al., "Parental Decision-Making After Ultrasound Diagnosis," *Fetal Diagnosis and Therapy* 20, no. 5 (September-October 2005): 321-7, p. 323.

42. Ibid., 324.

43. Ibid., 325.